EHMA 2025 Taking action to improve health for all

The experience of family caregivers along the palliative care pathway: a qualitative case study

Authors: Marzia C. Severino[1] , Sabina De Rosis[12]:
Marzia C. Severino[1] , Sabina De Rosis[12]

[1] Interdisciplinary Center Health Science and Management and Health Laboratory (MeS), Sant'Anna School of Advanced Studies
[2] Department of Law, Economics, and Human Sciences, University Mediterranea of Reggio Calabria

Background

Palliative care plays a crucial role in ensuring quality and continuity of care for patients with advanced chronic conditions in the context of growing demographic and social complexity.

Family caregivers are essential in this process, providing practical and emotional support, participating in care-related decision-making, and ensuring the patient remains in their social and family environment.

Despite their contributions to welfare systems in many countries, caregivers' roles and needs often remain under-recognized in both policies and care pathways.

Limited literature explores the global **caregivers' experiences** in **care pathways**.

Criticisms: lack of consensus on key dimensions; limited adaptability to various care contexts (Ringdal et al., 2002; Dy et al., 2008).

key dimensions for evaluating the global experience in the context of palliative care:

- **Psycho-physical aspects** (pain management and symptom control) (Tang et al., 2014);
- **Social and relational aspects** (respect, dignity, and communication with healthcare personnel) (Daly et al., 2013; Breitbart et al., 2015);
- **Environmental aspects** (quality of the care setting, whether at home, hospice, or hospital) (Zimmerman et al., 2014; Zhang et al., 2012).

However, existing tools often assess only some dimensions, leading to incomplete and inconsistently validated instruments across care settings (Abernethy et al., 2008; AIHW, 2014).

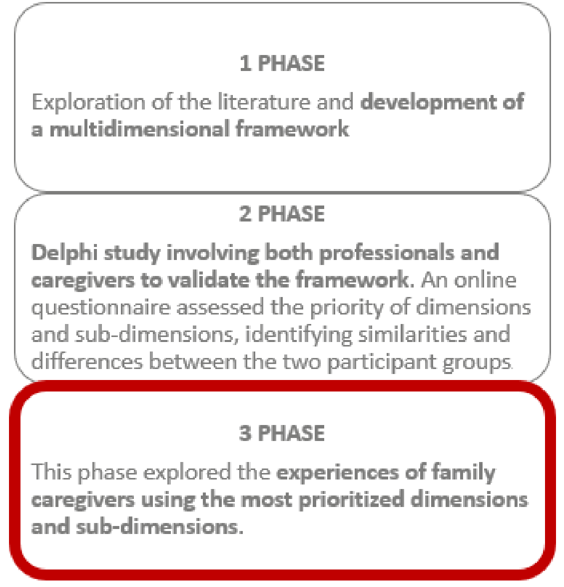
Aim

To **explore**, through a qualitative approach, the **experience** of informal **caregivers** along the **palliative care pathway.**

Provide **evidence** to **improve** the **quality** of **care** and **services** for both patients and their caregivers.

Data and methods

This **study** is **part of a multi-phase research project**. Phase 3, presented here, builds on earlier phases.



1 PHASE

Exploration of the literature and **development of a multidimensional framework**

2 PHASE

Delphi study involving both professionals and caregivers to validate the framework. An online questionnaire assessed the priority of dimensions and sub-dimensions, identifying similarities and differences between the two participant groups

3 PHASE

This phase explored the **experiences of family caregivers using the most prioritized dimensions and sub-dimensions.**

Data collection involved **two focus groups with family caregivers of deceased patients** recruited by professionals from the Palliative Care Functional Unit of Livorno.

Purposive sampling ensured diversity regarding **relationship** to the patient, type of **illness**, **gender**, **age**, and **care context**.

Two experienced psychologists specializing in palliative care facilitated the focus groups, while **an observer documented relational and non-verbal dynamics**.

Discussions were audio-recorded with informed consent, **fully transcribed**, and **analyzed thematically using NVivo** software.

Partecipants
15

13 women

2 man

Average age
50

Topic Guide

Needs

- Physical
- Social
- Emotional

Communication and Involvement

- Adequacy and consistency of communication by and among professionals
- Involvement of the family in defining the Individual Care Plan (ICP)
- Communication barriers

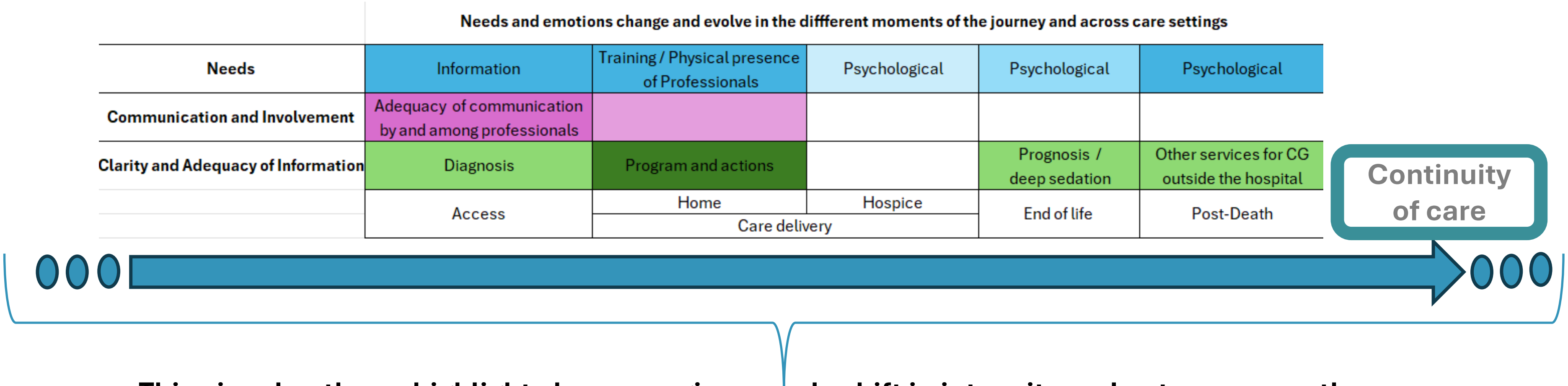
Clarity and Adequacy of Information

- Diagnosis
- Care plan and actions
- Prognosis

Exploratory and qualitative

Multidimensional approach

Frameworks are static…the caregiver’s journey is dynamic…



	Needs and emotions change and evolve in the diffferent moments of the journey and across care settings				
Needs	Information	Training / Physical presence of Professionals	Psychological	Psychological	Psychological
Communication and Involvement	Adequacy of communication by and among professionals				
Clarity and Adequacy of Information	Diagnosis	Program and actions		Prognosis / deep sedation	Other services for CG outside the hospital
	Access	Home	Hospice	End of life	Post-Death
		Care delivery			

This visual pathway highlights how caregiver needs shift in intensity and nature across the different stages of care, reinforcing the need for adaptable and phase-sensitive service models.

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THANK YOU

Marzia Severino marziacettina.severino@santannapisa.it
Sabina De Rosis sabina.derosis@santannapisa.it - sabina.derosis@unirc.it

ISTITUTO DI MANAGEMENT Sant'Anna Scuola Universitaria Superiore Pisa

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